

self with my shotgun. Blew a hole in the ceiling when she missed. She seemed okay afterwards, though."

He shook his head and shrugged. "Anyway, I'm doing great. I got married again. Happiest I've been in years."

I had been standing as he talked to me, but now I had to sit down so that I would not faint. Somehow, I made it through that visit. He even introduced me to his new wife.

She seemed quiet.

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Reflections of a "medical specimen" see also p.92

Mark Gash, Hollywood, CA

Mark Gash is a 43-year-old oil painter, actor, and Internet website designer who lives with his dog in an apartment in Hollywood, California. He also lives with osteogenesis imperfecta #3, a severely crippling skeletal disease. Mark's appearance has exposed him to decades of negative stereotypical misperceptions—by society and doctors—of people with developmental disabilities. He describes his experiences in this article, which was edited from a videotaped interview conducted by David Doostan, MD, and Michael Wilkes, MD.

Some of the most difficult parts of growing up disabled, especially when I was a kid, were people's social attitudes. In the 1960s, you very rarely saw anybody with a disability out in public. People with disabilities stayed home to avoid people's stares, pointing, and comments. Those things are becoming politically incorrect now, which is good. With my disability, it was hard for people to realize my age, and they would often talk to me like I was a little kid. When I was 8 years old, I remember I was in the store and somebody pointed at me and said, "Look, there's a baby!" I looked at him, and said, "I'm not a baby; I have osteogenesis imperfecta #3," and he just walked off, stunned. My father laughed about that for about 20 years.

School was difficult. I couldn't play in sports and didn't go out on dates, things like that, so I began to feel a little funny about things. Though I won "Friendliest Boy in the Seventh Grade" and had friends, there were many times when I had to go off for operations. I'd miss classes, and I'd have accidents in school. Besides the physical pain,

there's a lot of psychological pain, too, like having an accident in front of people. In junior high and high school, you don't want to look like that. That was hard. Accidents became more of a psychological problem than a physical problem for me.

Unfortunately, as I get older, the disability gets harder. Reality sets in: the reality of having to do things everyday, and learning how to do things differently, and having to be in a different social stratosphere. While other people are getting their own lives and families, I have to base my own lifestyle so much on my disability. My disability is always there to face. I have to think about it almost constantly. I have to be aware of what I'm doing and how I react to things, so I don't put myself in danger, and so that I can carry out daily functions. Many functions that people take for granted, I have to think out carefully. It frustrates me at times.



Mark Gash in front of his paintings

I have had a lot of problems with the medical profession. It was very difficult as a child to understand what was going on and the way I was treated. Groups of doctors would be hovering over me, yet they talked about me, never directly to me, so I began to feel like a specimen. There were many

times when I was stripped naked without any regard for me.

Since they almost never saw someone with osteogenesis imperfecta #3, they showed me around like a stamp or coin or something they would collect. I understand that doctors have scientific curiosity and interest, but at the same time, I am a human—I'm not a stamp to be collected, even if my case is interesting. I really have no problem with people learning something through seeing me, but I do have a problem when there's a lack of respect, a lack of sensitivity to my humanness.

Even as I got older, there were times when my bones were broken, and I was still talked about like a specimen, never talked to directly. It makes me feel kind of funny, makes me feel like a child. Doctors were seen as authority, figures by my parents, and so the doctors assumed greater authority. Doctors would say things in Latin or use medical terms, and my parents looked at me like they didn't know what was going on—that was very scary to me. But on many of those occasions, I would have had no reason to be scared if only the doctor had spoken in a way that we could understand.

I think that some doctors just see so many cases that they become insensitive to what they're really doing—working with a human being.

And doctors should realize that even though a disabled person's body may not be the same as another person's, they still need to respect that body. Undressing and staring at and speaking about and not directly talking to a disabled patient, even a child, hurts. Maybe the patients will not say anything but, really, it does affect their outlook on themselves for years to come.